

Iowa Department of Human Services

Terry E. Branstad Governor Kim Reynolds Lt. Governor Charles M. Palmer Director

December 14, 2012

Michael Marshall Secretary of the Senate State Capitol Building L O C A L Carmine Boal Chief Clerk of the House State Capitol Building L O C A L

Dear Mr. Marshall and Ms. Boal:

Enclosed please find the Outcomes and Performance Measures Committee report.

This report was prepared pursuant to 2012 Iowa Acts, Senate File 2315, Section 25.

This report is also available on the Department of Human Services website at http://www.dhs.iowa.gov/Partners/Reports/LegislativeReports/LegisReports.html.

Sincerely,

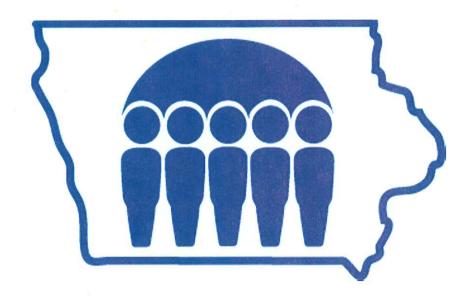
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Enclosure

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Iowa Department of Human Services



Outcomes and Performance Measures Committee Report

December 14, 2012

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Executive Summary

The Outcomes and Performance Measures Committee (OPMC) was established by Senate File (SF) 2315 and worked over the course of five public meetings and a conference call to present a framework and series of recommendations for the Department of Human Services (Department) to establish outcomes and performance measures for a continuous quality improvement system for the statewide mental health and disability service (MHDS) system.

SF 2315 establishes the expectation that MHDS services will provide individuals with effective treatment and the system will be efficient with the funds it expends. This expectation stems from two key concepts: 1) that individuals and family members depend on the state, counties (regions) and providers for quality, timely, effective services that will meet their needs and help them live meaningful, productive lives in their homes and communities; and 2) that tax payer dollars must be used as efficiently as possible. This report sets the course for the use of outcomes and performance measures to assess how well the MHDS system meets these expectations.

Recommendations

- The Department should develop an Iowa Mental Health and Disability Service
 Dashboard Report to demonstrate the performance and effectiveness of Iowa's MHDS
 system.
- 2. Outcomes and performance measures should fall within six domains. The domains are identified as follows, and described in further detail in the report:
 - a. Access to Services
 - b. Life in the Community
 - c. Person-centeredness
 - d. Health and Wellness
 - e. Quality of Life and Safety
 - f. Family and Natural Supports
- 3. The Department should use a survey process to collect and evaluate information directly from individuals and families receiving services and from the providers delivering these services.
- 4. The Department should convene a group of experts in survey development and outcomes and performance measurement to design the survey and assist in piloting the tool. The survey should be tested for validity and reliability, and OPMC and other stakeholders should have the opportunity to review the instrument as it is developed.
- 5. The Department should develop a budget that identifies the costs of implementing the outcomes and performance measurement system. The budget should include: initial and ongoing costs incurred at the state, regional and provider level; costs for the development and testing of the survey tool; costs incurred by providers for staffing and IT; costs incurred by the regions; and costs for training staff on performance measurement.

- 6. Only data that will be used should be collected, and the Department should convene a team to identify what information will no longer be collected.
- 7. Outcomes and performance measures should be reflective of the disability populations identified in SF 2315 and address all co-occurring disabilities.
- 8. Future decisions should be based on the information collected from the outcomes and performance measures system.
- 9. Outcomes and performance measures should be evaluated across both Medicaid and non-Medicaid systems.
- 10. Surveys should be conflict-free, meaning individuals and their family members will not be placed in a position to answer questions about outcomes and quality of services from those who directly provide services.

Introduction

In 2011, the Iowa Department of Human Services (Department), Iowa Legislature and stakeholders engaged in a mental health and disability services (MHDS) redesign effort that is transforming how services for people with disabilities are organized, administered, financed, delivered and evaluated. Senate File (SF) 525 set expectations for a MHDS system that ensures: equitable access to a uniform and integrated array of core services; services are cost effective and based on best practices; and services meet the goals of the Iowa Olmstead plan and support Iowans with disabilities to achieve the quality of life they desire in their home and communities. This effort resulted in reports that provided recommendations regarding the guiding vision and principles for the system; guidance on the administration of MHDS services; recommendations for a regional funding structure; and direction for best practice services across disability groups that are built upon a framework of continuous quality improvement. The reports were followed by the passage of SF 2315 that advances the redesign process.

Through SF 2315, the Outcomes and Performance Measures Committee (OPMC) was established to make recommendations for specific outcomes and performance measures to be utilized by the MHDS regional system. Membership for the committee was composed of stakeholders and consumer representatives across disability groups, as well as members of the Iowa Senate and House of Representatives (see Appendix C for a list of committee members). This report summarizes the work of the committee conducted between July and December 2012, and includes recommendations to guide Department activities moving forward. In December 2013, the Department will submit a final report.

OPMC Approach

SF 2315 outlines the following scope of work for OPMC:

"The committee's recommendations shall incorporate the outcome measurement methodologies previously developed by the mental health and disability services commission. To the extent possible, the committee shall seek to provide outcome and performance measures recommendations that are consistent across the mental health and disability services populations addressed. The committee shall also evaluate data collection requirements utilized in the mental health and disability regional service system to identify the requirements that could be eliminated or revised due to the administrative burden involved or the low degree of relevance to outcomes or other reporting requirements."

In contemplating this charge, OPMC recognized that as the redesigned system is developed policy and decision makers have an obligation to evaluate how the system is performing and if it is producing desired outcomes. This obligation stems from two key concepts: 1) that individuals and family members depend on the state, counties (regions) and providers for quality, timely services that will meet their needs and help them live meaningful, productive lives in their home and communities; and 2) that taxpayer dollars must be used as efficiently as possible.

OPMC built upon the framework developed in the redesign process, as well as previous efforts, to provide several recommendations for the Department to begin to implement an outcomes and performance monitoring system that can be used to evaluate the MHDS system, effectiveness of regions, and performance of providers as well as help guide decision making.

The recommendations were built on these efforts as well as the *Olmstead Principles: A Life in the Community for Everyone.*

- 1. **Public awareness and inclusion**...lowans increasingly recognize, value, and respect individuals with mental illness or disabilities as active members of their communities.
- 2. Access to services and supports... Each adult and child has timely access to the full spectrum of supports and services needed.
- 3. **Individualized and person-centered**...Communities offer a comprehensive, integrated, and consistent array of services and supports that are individualized and flexible.
- 4. Collaboration and partnership in building community capacity... State and local policies and programs align to support the legislative vision of resiliency and recovery for lowans with mental illness, and the ability of lowans with disabilities to live, learn, work, and recreate in communities of their choice.
- Workforce and Organizational Effectiveness... Investing in people through appropriate training, salary and benefits improves workforce and organizational effectiveness.
- 6. Empowerment...Communities recognize and respect the ability of people (1) to make informed choices about their personal goals, about the activities that will make their lives meaningful, and about the amounts and types of services to be received; and (2) to understand the consequences and accept responsibility for those choices.
- Active Participation...Individuals and families actively participate in service planning; in evaluating effectiveness of providers, supports and services; and in policy development.
- 8. Accountability and results for providers...Innovative thinking, progressive strategies and ongoing measurement of outcomes lead to better results for people.
- 9. **Responsibility and accountability for government**...Adequate funding and effective management of supports and services promote positive outcomes for lowans.

Consolidated Workgroup Global Outcome Recommendations

During the 2011 redesign process, the workgroups collaboratively developed a uniform set of outcome and performance measures to form the basis for system monitoring, quality improvement and accountability throughout lowa. The recommended measures at the systems, consumer and family level are listed below.

System Outcomes

- Help lowans increasingly recognize, value and respect individuals with mental illness and/or disabilities as active members of their communities.
- Provide each adult and child with timely access to the full spectrum of supports and services needed, including those who have co-occurring disabilities.
- Offer a comprehensive, integrated and consistent array of services and supports that are individualized, person-centered, flexible and culturally informed.
- Ensure that state and local policies and programs align to support the legislative vision
 of resiliency and recovery for lowans with mental illness, and the ability of lowans with
 disabilities to live, learn, work and recreate in communities of their choice, thereby
 reducing lowa's current reliance on high-cost institutional settings.
- Invest in people through appropriate training, salary and benefits to improve workforce and organizational effectiveness.
- Recognize and respect the ability of people to make informed choices about their personal goals, about the activities that will make their lives meaningful and about the amounts and types of services to be received, and to understand the consequences of, and accept responsibility for, those choices.
- Ensure that individuals and families actively participate in service planning, in evaluating effectiveness of providers, supports and services and in policy development.
- Encourage the use of innovative thinking and progressive strategies that lead to better results for people.
- Provide adequate and flexible funding and cost effective management of supports and services that promote positive outcomes for lowans.
- Ensure that children and adults receive the necessary services and supports to achieve their optimal educational potential.

Individual Outcomes

- People make choices about their lives including with whom and where they live.
- People have support to participate in their communities.
- People have friends and relationships.
- People have support to find and maintain meaningful, competitive, community integrated employment.
- People have transportation to get them where they need to go.
- People are safe from abuse, neglect, restraint, seclusion, injury and coercive interventions.
- People receive the same respect and protections as others in the community.
- People secure needed health services and are supported to maintain healthy habits.
- People's treatment, including medications, is managed effectively and appropriately.
- People receive information about their disability and the services and supports they

need in easily understood language.

- People are actively engaged in planning their services and supports.
- People are supported to be self-determining and to manage and direct their own services.
- People are supported to advocate for themselves.
- People have timely access to services and supports in the community that aid in preventing and resolving crises in a least restrictive, person/family-centered and minimally disruptive manner.
- People receive the necessary services and supports to achieve their optimal educational potential.

Family Outcomes

- Families have equal access to needed services and supports, including crisis intervention and respite, regardless of where they live and the nature of their family member's disability.
- Families receive accurate and accessible information and counseling regarding the nature of their family member's disability and relevant services and community resources.
- Family voice is sought and choices are respected and considered by the familyinclusive service team.
- Families have the information and support necessary to assist in the development of a plan for their family member.
- Families that choose to self-direct flexible budgets can do so (for families with children).
- Families receive supports necessary to keep the family together.
- Families get the services and supports they need to make a positive difference in their lives and the life of their family member with a disability.
- Families use integrated community services and participate in everyday community activities.
- Families are supported to maintain connections with and participate in the treatment of family members with disabilities not living at home.
- Families have a primary decision-making role in the care of their (dependent) children, as well as the policies and procedures governing care for all children.
- Families are given accurate, understandable and complete information necessary to set goals and to make informed decisions and choices about the right services and supports for (dependent) children and their families.

Taken together, the Iowa Olmstead principles and the outcome and performance measurement recommendations made by the redesign workgroups provide a comprehensive template that was used by OPMC to guide its deliberations and consensus building. OPMC worked over the course of five meetings and a conference call to begin to narrow this information into a more manageable set of domains and measures that can then be developed into tools for use by the Department.

OPMC Charge

OPMC discussed its charge, how it would define the success of its work, and how it could be most effective in helping the Department move forward. The committee recognizes that the actual work in implementing an outcomes and performance measurement system lies ahead. Rather than develop the actual tools that the Department would use, OPMC believed it could best provide clear instructions to the experts who will actually develop the tools over the next several months that will measure outcomes and system performance.

OPMC first defined what would constitute the success of its efforts:

- The actual performance measures and tools that are implemented must reflect the
 values on which SF 2315 is based as well as the types of outcomes and information that
 can be used to monitor the effectiveness and efficiency of the redesigned system. In
 this report, OPMC provides clear recommendations regarding the domains and types
 of outcomes and performance measures that the Department should collect.
- 2. The tools to be developed must have validity and reliability. Information must be collected directly from individuals served as well as from those who support them.
- 3. OPMC recognizes that it will be important to resist the temptation to collect data simply because it can be collected. Only data that will be used should be collected. OPMC recognizes that this is the beginning of establishing a system of continuous quality improvement, and that the committee should recommend a set of expectations that are sustainable given resource capacity.
- 4. OPMC expects that outcomes and performance measures be reflective of the disability populations identified in SF 2315 and address all co-occurring disabilities (i.e. mental illness, substance abuse and other addictions, intellectual/developmental disability, brain injury, etc.). The committee also suggests that outcomes related to disabilities and co-occurring physical health conditions be measured.
- 5. There must be shared ownership of a continuous quality improvement framework among the state, regions, providers, Medicaid managed care organizations, consumers and families. Data must be collected in a way that regional performance can be measured in the spirit of continuous quality improvement.
- 6. OPMC anticipates that the types of outcomes and performance measures recommended in this report will provide clear expectations for regions and the provider community. In addition, the committee expects that future decision making by the Department, regions, Medicaid managed care organizations and providers will be based upon information resulting from the outcomes and performance measures system.
- 7. The persons who administer portions of the outcomes and performance measure process (i.e. individual and family surveys) have appropriate training to do so. This will require adequate funding for training purposes.

- 8. The use of outcomes and performance measurement is viewed through a continuous quality improvement lens while supporting accountability for results. This will make accountability throughout the system more clear, including to the legislature.
- 9. There should be a public information component to the outcomes and performance measures work so that all stakeholders (including taxpayers) know what the investment in the MHDS system is producing.

Current Outcomes Climate in Iowa

Building a culture that measures and evaluates performance is an indicator that the system strives to achieve meaningful outcomes. This is an ongoing struggle for human services agencies throughout the country, and tends to be exacerbated during economic downturns such as the one the United States has been experiencing for the past several years. However, it is also during times like these that the use of outcomes and performance measures are critical to making disability services and financing systems decisions that are producing desired outcomes versus those that are not.

Like other systems, the Department collects a lot of information. Some of it is required by federal funding agencies like the federal Center for Medicare and Medicaid Services (CMS) and the Substance Abuse and Mental Health Services Administration (SAMHSA). Some of it is required by various state agencies or offices, including the Department of Management's State Budget Division, Iowa's Legislative Services Agency (LSA), the Division of Mental Health and Disability Services (MHDS), the Department of Inspections and Appeals (DIA), and the Iowa Medicaid Enterprise (IME).

Most of this information is generated and collected at the provider level, and may come from various sources, including:

- · Service coordination monitoring
- Record reviews
- Risk assessment results
- Satisfaction surveys
- Waiver audits
- Incident management data
- Complaint data
- Paid claims and financial audits
- Mortality reviews

Currently, information is collected and some of it is utilized for some decision making purposes. These include:

- Budgeting at the state and county level;
- Network and service plan development by the Medicaid managed care provider;
- · Agency/program licensure and accreditation; and
- · Policy and program development.

However, an organized approach to drive the system based upon performance and

outcome measures does not currently exist, largely because of lack of resource availability at all levels. It is important to note that there are costs associated with collecting, analyzing and using information to guide decision making at the department, county and provider levels. Moving forward, there will be costs to regions, too, as they are implemented. Costs typically include staff time and expertise associated with collecting and analyzing information and the necessary information technology infrastructure to collect and analyze data (i.e. electronic health records, manual surveys, etc.). Resources to measure and evaluate systems and services tend to be the first to be scaled back during difficult financial times, and the last to be ramped up when economic times are better.

OPMC recognizes and supports the essential investment that will be necessary for a meaningful outcome and performance monitoring system in order to assure timely access to appropriate, integrated, effective and cost efficient services. Consideration will need to be given to ensuring there are sufficient staff resources at the Department, regional, and provider level, as well as start-up and on-going funds associated with electronic information technology.

The absence of an organized, systematic and sustainable performance measurement system results in less than optimal accountability at all levels. In the current system, service recipients have few mechanisms to know if the services they are receiving are effective compared to other providers. Counties have limited ability to know if the services they are funding are producing desirable outcomes. The Department is uncertain if counties are funding best practices. The lowa Legislature is uncertain if the funding it allocates works its way into the best services that produce the best outcomes. In the future, regions will experience the same problems if there are no performance expectations.

lowa's situation is similar to other states in that the use of outcomes and performance measures to drive decision making has taken a back seat. However, the findings and recommendations in the redesign process identified the need for lowa to move in this direction, and the lowa Legislature signaled its support by creating OPMC. The work of OPMC constitutes the initial steps in the process of establishing a continuous quality improvement framework for MHDS services in lowa.

Recommendations

1. DHS should develop an Iowa Mental Health and Disability Service Dashboard Report.

The Iowa Legislature mandated that certain types of information be collected in SF 2315. These measures fit well into the domains identified by OPMC, which are further detailed in the second recommendation, and are reflected in Appendix B. These include the following:

- Access standards for required core services.
- 2. Penetration rates for serving the number of persons expected to be served,

particularly the proportion of individuals who receive services compared to the estimated number of adults needing services in the region.

- 3. Utilization rates for inpatient and residential treatment, including:
 - Percent of enrollees who have had fewer inpatient days following services.
 - b. The percentage of enrollees who were admitted to the following:
 - State mental health institutes;
 - ii. Medicaid funded private hospital in-patient psychiatric services programs;
 - iii. State resource centers; and
 - iv. Private intermediate care facilities for persons with intellectual disabilities.
- 4. Readmission rates for inpatient and residential treatment:
 - a. The percentage of enrollees who were discharged from the following and readmitted within 30 and 180 days:
 - i. State mental health institutes
 - ii. Medicaid funded private hospital in-patient psychiatric services programs
 - iii. State resource centers
 - iv. Private intermediate care facilities for persons with intellectual disabilities
- 5. Employment of the persons receiving services.
- Administrative costs.
- 7. Data reporting.
- 8. Timely and accurate claims payment.

OPMC went beyond these legislative mandates and developed the domains and types of survey questions and additional information in Appendices A and B that should be collected. This additional information can be incorporated into the dashboard report to further demonstrate the performance and effectiveness of Iowa's MHDS system. Within this dashboard approach, the Department should collect and evaluate information at the service recipient and system level. At the service recipient level, information should be collected directly from service recipients and their families through the use of a survey tool. The collection of information directly from service recipients will provide more meaningful information than if only collected from regions and providers, and will provide a further test, or check and balance, to results from system level information. The Department should update this report and make it available to the public on a regular

¹ For purposes of this report, OPMC considers family members as service recipients also.

² Surveys for family members may be provided when clients have acknowledged family member involvement and provided an appropriate consent, or for family members who have identified themselves as being a family member of someone with a disability.

basis. Over time, the Department should ensure that as the continuous quality improvement system develops, it is dynamic and can focus on various measures and outcomes as needed.

2. Outcomes and performance measures in the Iowa Mental Health and Disability Service Dashboard Report shall fall within six domains.

The domains encompass a broad spectrum of potential outcomes that should be evaluated. These domains should remain a guiding framework indefinitely while the types of questions or information that is collected may change over time. The domains are identified as follows:

Access to Services:

OPMC felt that access to services is a critical component to engaging in and receiving quality services. Legislative members of the committee also emphasized that this was important to the legislature. Too often, individuals with disabilities experience poor access to services for a variety of reasons, including insufficient funding that causes an absence of services or waiting lists, inconvenient location, rigid eligibility criteria, etc. By evaluating measures in this domain, OPMC expects that the system will use findings to continue to inform ways to improve access to services.

Life in the Community:

The OPMC agrees that every lowan should have the opportunity to live a life in the community, and that there are indicators that exist to measure the degree to whether regions, programs and services support individuals' ability to live successfully in the community. Within this domain, OPMC identified three subsets of information that should be collected – *housing*, *employment* and *transportation* – which the committee felt to be most closely aligned with a life in the community.

Quality of Life and Safety:

OPMC felt that physical presence in the community is not by itself an end goal and that one's quality of life and safety are important aspects to measure. Quality of life and safety broadly encompass many potential indicators, and the committee identified examples that measure an individual's connectedness to the community, perceived ability to make independent decisions, symptom and disability management, and whether living arrangements are safe.

Person-centeredness:

OPMC felt that measuring how well the system provides services based on a personcentered orientation was important enough to warrant its own domain. The committee was particularly interested in understanding potential differences in findings between service recipient responses in surveys and information collected from the provider level.

Health and Wellness:

OPMC recognized that the health and wellness of service recipients is as important to people with disabilities as coping with the disability itself. Unfortunately, the disabilities services and primary care communities have not paid enough attention to the health

and wellness of people with disabilities. OPMC felt strongly that the Department should, in collaboration with the primary care community, play a role in measuring and evaluating health and wellness outcomes of people with disabilities.

Family and Natural Supports:

The committee recognized that, for many service recipients, the Department is working in collaboration with the recipient's families to ensure well-being and health. By evaluating measures in a domain like this, the system can better understand regional, provider or programmatic difference and strengths that can help inform how family and natural supports affect the lives of service recipients. OPMC recognized that people with disabilities often have strained or damaged relationships with family members, and often lack natural supports that can help them. Therefore, not all service recipients want to have or restore relationships with families, but that there may be programs, services or other interventions that may help improve these situations which can lead to more positive outcomes.

3. The Department should use a survey process to collect and evaluate information directly from individuals and families receiving services and from the providers delivering these services.

Appendices A and B are critical documents to this report and represent the core of the committee's recommendations. Appendix A provides examples of types of questions, by domain, that OPMC felt should be part of a service recipient-level tool. Appendix B provides examples of the types of information, by domain, that OPMC felt should be collected at the system level through provider, regional and other available information. Several of these are already collected and required as part of federal or national reporting requirements (e.g. penetration rates).

The collection of information directly from service recipients will provide more meaningful information than if only collected from regions and providers, and will provide a check and balance to results from system level information. As discussed above, rather than develop the actual tools that the Department would use, OPMC believed its role was to instruct the types of information that should be collected and evaluated while leaving the development of specific tools, measures and questions to those with expertise in outcomes and performance measurement. The suggested measures are not an exhaustive or comprehensive list of potential measures to be collected, and MHDS, IME, and regions may collect other outcomes and performance measures for management purposes. It is expected that portions of these measures may change over time to meet the evolving needs of the system for decision making.

OPMC also discussed the need to gather sufficient information from service recipients so that informed decisions can be made regarding performance at the state and region levels. While the OPMC was interested in evaluating how well lowa performs overall, it focused much of its discussion on the need for regional comparisons and provider performance. Consequently, this affects the sampling size and survey methodology to ensure reliable and valid results. There are several variables to consider when developing the sample size. If only a statewide approach was used (i.e. surveying different disability

populations in one pool for the whole state), approximately 400 completed, valid surveys would be needed based on numbers of people across disabilities served in SFY12. However, SF 2315 requires regional comparisons, and OPMC felt this was far too limiting to yield good information at the regional and provider level. However, in developing the survey tool for service recipients, OPMC suggests that 400 is a reasonable number in a pilot phase to start testing the survey.

OPMC recommends that at a minimum, the Department should administer enough surveys to be able to compare outcomes across regions. Regional composition has not yet been determined, and will affect sampling methodology as they are developed. The committee advises the Department to be careful not to make blanket comparisons across regions because they have differing geographical or demographic characteristics. The committee further recommends that sampling within regions be randomly selected from service recipients across disabilities. For OPMC purposes, the Department drew up 17 hypothetical regions and used a sample size calculator to determine the hypothetical sample size needed to capture valid and reliable results. Based on this information, 4,783 total surveys would need to be completed. In this same scenario, if individuals are divided across 17 hypothetical regions and by population group (i.e. MI, ID, DD, BI), then 11,602 people would need to be surveyed in order to able to compare the survey results across regions and across population groups.

Recognizing resource limitations, OPMC suggested a possible approach of capturing all of the data for the first assessment and then moving to a three-year assessment cycle after that. This is the method that is currently used by IME to collect survey information for its Home and Community-Based Services (HCBS) waivers. IME collects information from approximately 1,800 people over the course of each three year cycle for individuals on the HCBS waiver.

Specific to the mental health population, OPMC also discussed who information should be collected from. The committee generally felt that all individuals with mental illness who engage public mental health services should be considered in this process, particularly as the field evolves to more prevention-based activity. However, mental illness is broad in scope, and many individuals with less severe forms of mental illness may only engage the mental health system for a brief period and never return; whereas, people with severe mental illness (SMI) often have more ongoing challenges related to functioning, and remain engaged or known to the mental health system for an extended period of time. OPMC recognized that resource limitations may impede the Department's ability to gather systems information and implement surveys for other than persons with an SMI. Over time, however, OPMC recommends that the Department incorporates measures for anyone who engages publicly funded mental health services. For other disabilities, OPMC recommends that no distinction be made for survey purposes.

4. The Department should convene a group of experts in survey development and outcomes and performance measurement to design the survey and assist in piloting the tool.

In developing Appendices A and B, OPMC identified a range of challenges and considerations for the Department in finalizing instruments, and OPMC recommends that the Department seeks the assistance of those with expertise in research and outcomes evaluation to design the actual tools based upon recommendations in this report. However, OPMC and other stakeholders should have the opportunity to review the instrument as its development progresses.

OPMC discussed whether to use existing survey instruments that are used in various settings across the country [e.g. National Core Indicators (NCI), Mental Health Statistics Improvement Program (MHSIP)] or tools that are Iowa-specific. Some members expressed concern that the development of an Iowa-specific tool might sacrifice the comprehensiveness and quality of results, and that good tools already exist. However, OPMC recommends the development of an Iowa-specific tool for outcomes and performance measurement.

The committee wants to ensure that outcomes are evaluated across several domains, and many existing tools address a more limited scope of outcomes or were designed specifically for one disability population. OPMC reached consensus to use these domains as a way to build upon the work that has been done previously to define the MHDS system values, and ensure that the dashboard approach is consistent with those values.

Consistent with the legislation, OPMC also wants to employ a cross disability approach to outcomes evaluation, and existing tools also tend to be disability specific. The committee is also concerned that applying several different tools in order to cover each domain could overwhelm respondents, and that randomly applying several different tools to subsets of the population would become too complex. While developing an lowaspecific tool will require piloting to test its reliability and validity, the committee generally felt this approach would best meet the system's objectives. OPMC recommends that survey and information collection instruments should be piloted in 2013 to ensure that the right type of information is being collected to evaluate the desired outcomes. The committee also recommends using survey methods that will limit the amount of respondent judgment and bias in questions, and that consumer and family surveys are brief and minimize burden to providers for collecting information.

Several of the questions listed in Appendices A and B are used in other existing survey tools (e.g. MHSIP, NCI) that have been tested for reliability and validity. While a compilation of questions from other survey instruments does not automatically constitute a valid, reliable tool, it does provide a basis for the development of lowa's survey. The specific questions are provided to illustrate the targeted content area and types of questions that OPMC believes should be reflected in the survey. The committee expects that those charged with developing the actual tool may refine certain questions in order to ensure that the intended question produces good data for the Department. OPMC further

advises that the final questions should not confuse licensing standards with outcome measurement. Licensing standards are designed to ensure that minimum standards are met for providers to be eligible to deliver services. Outcomes and performance measurement systems are designed to measure, evaluate and drive performance to meet intended outcomes.

5. DHS should develop a budget that identifies the costs of implementing the outcomes and performance measurement system.

OPMC recommends that the Department remain cognizant that any outcomes and performance measurement system must be meaningful, practical, realistic, and not present an undue financial burden to the system and providers. Within this overall context, OPMC recommends the Department develop a budget that identifies the costs of implementing this system. The budget should include: initial and ongoing costs incurred at the state, regional and provider level; costs for the development and testing of the survey tool; costs incurred by providers for staffing and IT; costs incurred by the regions; and costs for training staff on performance measures. However, the Department should not allow development of this budget to delay implementing the outcomes and performance measures that can be collected with information that is already available in the MHDS system, and cautions against collecting so much information that the ability to deliver services is compromised. OPMC recommends that data should be collected and shared as frequently as practical, but no less than on a monthly basis. The committee also recommends that the collection of information is not redundant, duplicative or in conflict with other systems that exist or are in the process of being developed (e.g. Health Insurance Exchanges).

6. Only data that will be used should be collected.

In weighing the need to collect good information, resources limitations, and information that is currently collected that provides minimal value, the committee discussed a process to determine how to go about eliminating or reducing certain types of information that are now collected. OPMC recommends that the Department convenes a task oriented group of providers, regional staff, county staff, state staff and consumers who are intimately aware of the information now collected to identify the specific types of information that the Department and DIA should no longer collect. The Department should be prepared to present the types of information currently collected to the task group members prior to the meeting so that the recommended list of information can be identified for the Department in this meeting.

OPMC also recommends that in finalizing the type of data to be collected, the Department does not avoid asking certain types of questions if related services do not yet exist in a region. The information collected is intended to inform decision-making. For example, if employment outcomes are poor because there are limited or no employment related services, the Department could use this information to allocate existing funds or request additional legislative appropriations to fill the void.

7. Outcomes and performance measures should be reflective of the disability populations identified in SF 2315 and address all co-occurring disabilities.

Co-occurring disabilities include, but are not limited to, mental illness, substance abuse and other addictions, intellectual/developmental disability, and brain injury. The committee suggests that outcomes related to disabilities and co-occurring physical health conditions be measured while not forsaking relevant information associated with specific disabilities. The Department should consider how to collect information that is highly relevant to specific disability groups. For example, some health and wellness domain questions are relevant across all disability groups while questions related to smoking and drugs/alcohol use (health and wellness domain) have much more relevance to the mental health population than other groups.

- 8. Future decisions should be based on the information collected from the outcomes and performance measures system.
- 9. Outcomes and performance measures should be evaluated across both the Medicaid and non-Medicaid systems.
- 10. Surveys should be conflict-free, meaning individuals and their family members will not be placed in a position to answer questions about outcomes and quality of services from those who directly provide services.

OPMC recommends that the use of trained or certified peer specialists be considered for this role.

Next Steps

The Department can implement the outcomes and performance measures in a staged process. Much of the system level data is already available through claims processing data so the Department will begin establishing dashboard measures using this data first. Other measures can come from additional data gathered from providers or regions. The Department will expand use of dashboard measures using this additional data once it is developed and reviewed by the OPMC.

Finally, this report is intended to be the platform for the Department to develop and test pilot a survey tool and information collection for individuals served and their families. It is anticipated that the Department will work with outcomes and performance measurement experts to finalize the specific questions, types of information, survey tools and sampling size. It is also anticipated that the Department may need to rely on these experts to evaluate and interpret the results of the pilot process to advise in the adoption of the final tools that the Department will use to collect information.

The Department agrees to share its progress with OPMC and key stakeholders, and develop a systematic method for gathering feedback, as the dashboard and measurement tools are developed and tested. This should enable OPMC to advise the Department. The Department should also report publicly on its implementation progress.

Appendix A Types of Consumer/Family-Level Outcome Measures

Assessment Tool	MHSIP, NCI, IPES	MHSIP	ON N		MHSIP	
Currently Collected in Iowa?	0 0 2 2	o o	o 2		N N	Yes
Domain	Access to Services	3				
Question/Measure	 I am able to get all of the services I think I need. If I am in an emergency, I know who to contact. 	 I know how to access services. The location of services is convenient for me. 		 o. The last time inequested to see my doctor; it was able to see my doctor: o. On the same day o. The next day o. Within 5 days o. Within 1 – 2 weeks o. Within 1 – 6 month 	 7. The last day I requested to see my psychiatrist, I was able to see my psychiatrist: • On the same day • The next day • Within 5 days • Within 1 – 2 weeks • Within 1 – 8 month • Within 1 – 6 months 	8. I am on a waiting list for services. If yes, please list the services you are waiting for.

o	No PES, RLQS, NCI	No PES, RLQS No PES, Workgroup No PES, Workgroup	No No	No No	No PES, NCI Yes Lancanshire, NCI,	No No PES, NCI, CIQ
18.50 2	Life in the Community Housing		·		Life in the Community Employment	Life in the Community Transportation and Other
 9. The location of my medical services is convenient for me to get to. 10. I have lost access to services in the past year. If Yes, why? 41. I have lost access to defert to get the conjuger I needed 		13. Do you have a lease?14. If you live with others:I chose whom to live with.	 I share a bedroom. I would prefer to live alone. 15. I feel like part of my community. 	 My housing situation has improved since receiving services. I have positive interactions with some neighbors. 	18. Do you want to work? 19. Do you earn money at your job? If yes, Do you like your	20. I live close to food shopping and other community resources?

22. Does your community transportation meet your needs? If not, why not? 23. I participated in the development of my service plan. 25. If alsagree with something in my person-centered plan. 26. If alsagree with something in my person-centered plan. 27. The staff take my preferences into account in recommending what my treatment and service plan should be. 28. The staff take my preferences into account in recommending what my treatment and service plan should be. 29. The staff take my preferences into account in recommending what my treatment and service plan should be. 29. The staff take my preferences into account in recommending what my treatment and service plan should be. 29. The staff take my preferences into account in recommending what my treatment and service plan should be. 30. I have been given information about my rights. 31. I plan and schedule my daily activities. 32. Staff respect my wishes about who is not to be given information about my treatment. 33. In general, would you say your health is: Excellent, Very Good, Good, Fair, Poor 34. In general, staff listen to me and respect my decisions 34. In general, staff listen to me and respect my decisions 35. In general and are.	21. Do you have access to transportation? Public or private?	Amenities	No	NCI
an, I hould to be Health and Wellness Yes Yes Yes Yes Yes Yes Yes Yes Yes	unity transportation meet your needs? If			
an, I tr. hould hould hould to be Wellness ery No No No No No No No No No N	ne development of my service plan.	Person- centeredness	N N	MHSIP, NCI, IPES
Id No	upports identified in my service plan.		o Z	NCI, IPES
e plan should ny No No No No o is not to be Health and Wellness Ares	something in my person-centered plan, I portunity to express my disagreement.		o Z	ÖZ
e plan should No No No o is not to be Health and Wellness Yes Allent, Very Health and No	omes to my meetings.		o N	
S not to be Health and Wellness Wellness No No No No No No No Sisions	ny preferences into account in what my treatment and service plan should		o _N	PES
s not to be Health and Wellness Wellness No No No No No No Sisions	sitive and accommodating to my		Yes	MHSIP, RSA-R
ights. d who is not to be Excellent, Very my decisions No No No No No No No No	ackground.	-	N _O	PES, NCI
No No Health and Wellness Yes	and well-treated by staff.		oN N	NCI, MHSIP, IPES
Health and Wellness Yes	en information about my rights.		o _N	MHSIP
Health and Wellness Yes			Z	MHSIP
Health and Wellness Yes	y wishes about who is and who is not to be on about my treatment.		2	
Yes		Health and Wellness		
and respect my decisions	ıld you say your health is: Excellent, Very air, Poor		Yes	CHI, MHSIP, Lancanshire
			No	RSA-R

47. I am happy with the friendships I have.	N	La l	Lancanshire Lancanshire, NCI
48. I feel lonely.	OZ		~MHSIP,
49. I have the family support that I want.			Workgroup
	pı s		
50. I am satisfied with my level of involvement in supporting Par Meas my family member.	ramily No Measures		
51. I had to spend a lot of effort to get my family member the services they needed.	o Z		
52. I receive accurate and accessible information and counseling regarding the nature of my family member's disability as well as relevant services and community	OZ		横
resources.	^o N		
53. I know how to access family support services.	°Z		
54. My voice is sought and choices are respected and considered by a family-inclusive service team.	0 <u>N</u>		
55. I am invited to assist in the development of a plan for my family member.	OZ		
56. Confidentiality laws limit my ability to assist my family member.	9 N		×
57. I get the services and supports I need to make a positive difference in the life of my family member with a disability.	<u>8</u>		
58. I have access to support and resources to support my family member at home.			

	Quality of Life/Safety		
59. I feel safe in my own living environment.	•	No	
60. I make my own decisions.		No	RSA-R
61. I feel comfortable in social situations.		No	MHSIP
62. The services I receive help me deal more effectively with daily problems.		ON.	CHI, MHSIP
63. The services I receive help me to do better in school and/or work.		O Z	MHSIP
64. I am better able to do things that I want to do.		0 Q	AISHINI AISH MHO
65. My symptoms are not bothering me as much.		2 2	Workgroup
66. My self-esteem has improved as a result of receiving services.		2 O	RLQS, NCI, IPES
67. I feel like I might be harmed in my community.		Yes	Lancanshire, Lancanshire
68. Have you had any involvement with law enforcement in the past 6 months?		o Z	
69. I know what to do if I'm in a situation where I don't feel safe.			

List of Assessment Tools

- CHI (Consumer Health Inventory): Used by Magellan to collect consumer outcome information. Some of the data collected is reported as part of the lowa NOMS
 - CIQ (Community Integration Questionnaire): Used to assess community integration in the Brain Injury
- IPES (lowa Participant Experience Survey): Used to evaluate IME's HCBS waiver participants' experience.
- Lancanshire (Lancanshire Quality of Life Profile): Developed in England to assess consumer quality of life
- by SAMHSA to collect consumer outcome information for NOMS. States have the option to develop their own tool. MHSIP (Mental Health Statistics Improvement Program Consumer Survey): The standardized tool developed
- Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) and used for the purpose of NCI (National Core Indicators): Developed by the National Association of State Directors of Developmental Quality Improvement (QI).
 - PES (Participant Experience Survey): Survey for ID/DD population that was discussed in 2006 by the MHDS Commission.
- RLQS (Real Life Quality Standards): Parts of this tool were used to evaluate the Family 360° grant.
- Recovery and Community Health to assess the degree to which programs implement recovery-oriented practices. RSA-R (Recovery Self-Assessment-for a person in recovery): Tool developed by the Yale Program for

General Survey Concerns from Committee Members:

- There should be questions for each domain asking if that area is important to the consumer.
- Not all of the questions listed are relevant to all disability groups. Accordingly so, response options should include a "not applicable" option.
 - List out activities that provide measures of community inclusion for question 13.
- All (or most) of the consumer measures in the family and natural supports domain have a positive slant.
- DHS should consider evidence based survey strategies for persons with disabilities when implementing surveying
- These measures should use person-first language when constructing the final survey tool.
- The consumer survey should be short enough to be completed within a reasonable timeframe.

Appendix B Types of Provider & System Data to be Collected

This chart contains recommended measures to be collected from both service providers and funders.

	N	Measures	Domain	Data Sources	Currently
					Collected in lowa?
			System Performance Measures		× ki
Υ.	1. Administrative costs		Required per SF 2315	Regions	Somewhat
2	Data reporting		Required per SF 2315	Regions/Providers	O Z
<u>ო</u>	Timely and accurate claims payment	payment	Required per SF 2315	Regions/Medicaid	No-county Yes-Medicaid
			Access to Care		
4.		Regions have standards to access required core services.	Required per SF 2315	Regional Management	o _N
ري	•	Penetration rates for serving the number of persons expected to be served: The overall proportion of individuals with mental illness, intellectual disability, or brain injury served.	Required per SF 2315	7. ??	Medicaid-Yes Non-Medicaid- partial
9	 Utilization rates for inpatient and residential treatment: The percentage of enrollees who were admitted to following: 	t and residential treatment: lees who were admitted to the	Required per SF 2315	Claims Data	Yes
	State mental health institutes - Medicaid funded private hosp services programs	State mental health institutes Medicaid funded private hospital in-patient psychiatric services programs			

Measures		Domain	Data Sources	Currently
				Collected In Iowa?
 State resource centers Private intermediate care facilities for persons with intellectual disabilities 	ities for persons with	,		
 Percent of enrollees who have had fewer inpatient days following services. 	d fewer inpatient days		Claims Data	Medicaid-Yes Non-Medicaid-
 7. Readmission rates for inpatient and residential treatment: The percentage of enrollees who were discharged from the following and readmitted within 30 and 180 days: 	n the	Required per SF 2315	Claims Data	No Yes
- State mental health institutes - Medicaid funded private hospital services programs - State resource centers	ital in-patient psychiatric			14
 Private intermediate care facilitie intellectual disabilities 	ities for persons with			
8. Number of providers with waiting lists.	Ś		Providers	Medicaid-Yes Non-Medicaid-
9. Number of regions with waiting lists.			Regions	No Yes-county
10. Average length of time on waiting lists.	its.		Medicaid/Counties	S ON
 Percent of people receiving services who are in an evidence-based practice. (Assertive Community Treatment, Supported Employment, Supported Education, Permanent Supportive Housing, Family Psycho-education, Peer Support, Self-help) 	who are in an evidence- nity Treatment, Supported Permanent Supportive Peer Support, Self-help)		Providers/Case records	o N
12. Percent of providers that have evening	ing and weekend hours.		Providers	_S
13. Number of enrollees without health insurance who are denied	insurance who are denied			

Measures	Domain	Data Sources	Collected in	
access to services due to lack of funding.		Medicaid/County	Yes	
14. Percent of dollars spent on inpatient versus community services.		Regions/Medicaid	Medicaid-Yes Non-Medicaid- No	
15. Percent of providers that have multi-lingual licensed clinical staff.	=	Providers	2 2	
16. Number of providers with co-occurring capacity.		Providers	2	
17. Percent of enrollees with access to Emergency Departments or Crisis Services.		Providers	No	-
18. Percent of enrollees that have their own lease.	Life in the Community: Housing	Provider	°N	
19. Percent of enrollees receiving housing assistance		Provider	No V	
 20. Type of Housing Setting: Independent apartment With family Supervised Apartment Shared living situation, lease-based Group Home, less than 6 people Group Home, 6-15 people Residential Care Facility, 6-15 people Residential Care Facility, over 15 people 	•	Provider	Yes	
Nursing Home Homeless Other		e	0.	

	Measures	Domain	Data Sources	Currently Collected in
				lowa?
21. The percentage of enrollee <i>Integrated housing means:</i> based setting of their choo individuals in the complex considered to be disabled.	21. The percentage of enrollees who live in integrated housing. <i>Integrated housing means:</i> an individual lives in a community based setting of their choosing, in which no more than 25% of individuals in the complex or surrounding neighborhood are considered to be disabled.		Provider	o _N
22. Percent of enrollees who p toward housing expenses.	22. Percent of enrollees who pay more than 30% of their income toward housing expenses.		,	:
23. Length of time consumer h	23. Length of time consumer has lived in their current housing.		Case Management	0
24. Number of enrollees that h days.	24. Number of enrollees that have been homeless in the past 90 days.		Provider	o N
			Provider	No
7.00 mm		Community: Employment	3	>
25. Is the Individual employed ?	\.	Required per SF 2315	Provider	res
 26. If yes, in what setting is the individual employed? Facility Based Employment: Employment in w of individuals have disabilities and is typically facility owned, leased, rented, or managed by 	es, in what setting is the individual employed? Facility Based Employment: Employment in which the majority of individuals have disabilities and is typically located in a facility owned, leased, rented, or managed by a service	Required per SF 2315	Provider	S N
provider. Group Integrated Empl	provider. Group Integrated Employment: Employment in which a group			
of individuals with disal community business wides with disabilities.	of individuals with disabilities are integrated in a typical community business where most people do not have disabilities.			
 Integrated Employment with a disability is empl 	Integrated Employment: Employment in which an individual with a disability is employed in the general workforce.			
 Self-Employment: Emp disability's primary emp 	Self-Employment: Employment in which an individual with a disability's primary employment and income is from a business			

	Measures	Domain	Data Sources	Currently Collected in
they own or operate				
27. How many hours did the ir	27. How many hours did the individual work in the reporting period?		Provider	ON.
28. Total gross wages earned during reporting period	during reporting period		Provider	No
29. Percent of providers with policies in place involvement in developing service plans.	29. Percent of providers with policies in place that require consumer involvement in developing service plans.	Person- centeredness	Providers	ON.
30. Percent of providers with documentation in rethat the client participated in service-planning	30. Percent of providers with documentation in record that indicates that the client participated in service-planning		Providers	No
31. Number of providers who has management.	31. Number of providers who have received training in medication management.	Health and Wellness	Providers	No
32. Date of client's last dental visit.	visit.		Case Records	No
33. Percent of enrollees who r	33. Percent of enrollees who receive active care management.	•	Providers	N _O
34. Percent of enrollees who h the past year.	34. Percent of enrollees who have received primary care services in the past year.		Case Management	<u>8</u>
35. Percent of enrollees who manage their independently.	nanage their medications		Case Records	0 2
36. Percent of total enrollees screened for	screened for Body Mass Index (BMI).		Provider	No.
37. Percent of enrollees screened for diabetes.	ned for diabetes.		Provider	N _o
38. Percent of enrollees screened for depression.	ned for depression.		Provider	No

Measures	Domain	Data Sources	Currently Collected in Iowa?
39. Percent of total enrollees screened for smoking.		Provider	oN O
40. Percentage of enrollees screening positive for smoking.		Provider	No
41. Percent of enrollees screened for alcohol or drug use.		Provider	o N
42. Percentage of enrollees screening positive for alcohol or drug use.		Provider	o _N
43. Percent of enrollees enrolled in physical health program (wellness groups; smoking cessation programs; alcohol or drug treatment; diet and exercise programs).		Provider	o N
	Family and Natural		2
44. Percent of enrollees who allow sharing of information with family members, broken down by provider.		Provider	o N
45. Of those who have a release permitting information sharing with family or significant others, the percent of records where staff have documented outreach and engagement.	12	Provider	N 0
46. Number of family support groups that are provided within the Region.		Regions	N N
47. The number of Information and Referrals made to family members regarding relevant services and community resources available in each Region.		Regions	ON No
48. Percent of enrollees whose financial status improved in the past year.	Quality of Life/Safety	Provider	No

Measures	Domain	Data Sources	Currently Collected in Iowa?
49. Percent of enrollees who experienced a reduction in symptoms based on standardized assessment.	in symptoms	Standardized Assessments/ Providers	°Z
50. Number of residential providers who have been cited for having life safety violations in the past year.Residential Care Facilities	ed for having	DIA	Yes
 State mental health institutes Medicaid funded private hospital in-patient psychiatric services programs State resource centers Private intermediate care facilities for persons with intellectual disabilities 	nt psychiatric rsons with	E.	
 51. Number of incidents involving injuries that required medical attention in the past year in: Residential Care Facilities Day programs State mental health institutes Medicaid funded private hospital in-patient psychiatric services programs 	i medical nt psychiatric	IM	Medicaid-Yes Non-Medicaid- No
State resource centersPrivate intermediate care facilities for persons with intellectual disabilities	rsons with		

General Survey Concerns from Committee Members:

- Be sure to define co-occurring capacity in a way that is consistent with SF 2315.
- measures needs to take into consideration individuals who receive more than type of employment service. Be sure to define employment definitions in a way that is consistent with SF 2315. The collection of these
- Not sure how to operationalize the definition of integrated housing in question #23.
 - Be cautious of letting this turn into a licensing survey.
- These measures are intended to create an atmosphere of continuous quality improvement.
- These measures should use person-first language.

Appendix C Types of Consumer/Family-Level Outcome Measures

Outcomes & Performance Measures Workgroup Charge

Source: Iowa Department of Human Resources (DHS), SF 525 and SF 2315 Date Created: July, 11 2012

Mission

To develop recommendations for a set of standard outcome and performance measures to be used to assess the effectiveness and efficiency of the regional mental health and disability services (MHDS) system.

Goals

- Develop performance and outcomes measurements that assess the effectiveness and efficiency of the MHDS system.
- Make recommendations for data collection requirements.
- Make recommendations for data collection methods.

Tasks

- Review previous work by the MHDS Commission with regards to outcome measurement.
- Review outcome measures used in the current MHDS system.
- Recommend outcome and performance measures that are consistent across the MHDS regional system.
- Recommend outcome and performance measure data collection methods that efficiently and effectively assess the MHDS system
- Identify and recommend current data collection efforts that can be revised or eliminated to reduce administrative burden.
- Coordinate with the Service System Data Statistical Information Integration Workgroup regarding methods of data collection.

Appendix D Workgroup Membership List

Outcomes and Performance Measures Committee

Chair-Rick Shults	DHS-Division of Mental Health and Disability Services	Division Administrator
Co-Chair-Bob Bacon	University of Iowa Center for Excellence on Disabilities, Center for Disability & Development	Director
Diamond, Diane	DHS-Targeted Case Management (TCM)	Bureau Chief
Harker, Becky	Iowa Developmental Disabilities Council	Executive Director
Hoffman, Chris	Pathways	Executive Director
Johannsen, Mike	Muscatine County	Central Point of Coordination
Lange, Todd		Mental Health Consumer
Lauer, Geoffrey	Brain Injury Alliance of Iowa	Executive Director
Matney, Liz	Iowa Medicaid Enterprise (IME)	Quality Assurance for Home and Community Based Services
Peterson, Mike		Parent of Intellectual Disability Consumer
Stone, Kathy	Iowa Department of Public Health	Division Director
Turvey, Dr. Carolyn	University of Iowa Department of Psychiatry	Clinical Psychiatrist
VanNingen, David	Hope Haven	Chief Executive Officer
Rep. Cindy Winckler	Iowa House of Representatives	State Representative
Rep. Joel Fry	Iowa House of Representatives	State Representative
Sen. Jack Hatch	Iowa Senate	State Senator
Sen. Joni Ernst	Iowa Senate	State Senator